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ABSTRACT

This presentation outlines the approach to integrated living for severely disabled individuals which was developed by Independent Living for the Handicapped of Brooklyn, New York. After a brief overview of the history and philosophy of this organization, the 'how-to' approach is explained. This program model coordinates services which are generally available to the non-handicapped population, toward the goal of independent living for severely disabled persons. The 'how-to' approach is explored from the viewpoint of a person in a wheelchair: how to find an apartment; how to be assertive; how to cope with daily living problems, such as, how to supervise home staff, how to fire someone, how to budget, and how to shop and use free time creatively. The government funding which is available to a person who chooses this lifestyle is presented, as well as the support services which may be needed to obtain these entitlements. A definition is offered. In addition, component parts of this program model, such as an Emergency Aide Service and a Specialized Livery Service, are presented. The assets and deficits of this community based non-medical model are discussed, as well as an evaluation of accountability in light of the partnership which develops between people who are disabled and people who are not. (Author)

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INTEGRATED LIVING FOR SEVERELY DISABLED PEOPLE: A RADICAL APPROACH

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A presentation which advertises itself as "a radical approach" runs the risk either of alienating those people whom it most wants to address or of attracting those people who may want to contest its claim, or support its rightness. However, this was not the author's conscious intention when he entitled this paper. Another idiosyncrasy which has grown up around the phrase "a radical approach" offers a definition of "radical" as "going back to the roots": the implication, of course, is "Now, we are going to do it right!"

For what reasons did this author choose the phrase "a radical approach"? Is the approach of Independent Living for the Handicapped, Inc. to lifestyle options for disabled people a radical approach because it is not the medical model approach? Is it a radical approach because it is a grass roots movement approach? Is it a radical approach because it is totally a community-based approach? Or, is it a radical approach because it combines the dream of some disabled people and the dedication of some non-disabled people? It is a radical approach because it is all these things and more!

In choosing this phrase, "a radical approach", the author acknowledges the baggage which the phrase carries with itself, and it is his hope that the weight of this phrase can be used as a lever to assist the reader move from his present position to another one. This movement affords the reader at least two perspectives to view the situation before him. This author claims no right position, only the position which Independent Living for the Handicapped,

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Inc. has found to work for some disabled people; he offers this program model, with its assets and deficits, for consideration.

Independent Living for the Handicapped, Inc. is a small voluntary non-profit organization which was started in the mid-1950's as a recreation program for dystrophic children by their parents, relatives, and friends. These dedicated individuals banned together to give their disabled children the same social opportunities as their non-disabled peers. In their 1957 Souvenir Journal, Mary Weinberger, the founder of the organization, wrote:

> "There is no doubt that muscular dystrophy handicaps -- but do we have to increase the handicap by shutting our eyes to the fact that the MD person is human and wants to live a little? We trained teen-age boys to handle the MD child and young adult -- not only did these attendants learn how to dress, and handle the young people -- it also gave them the opportunity to learn that the MD person is a human being -- has every much the same likes and dislikes they themselves have. The MD children for the first time in their lives had the opportunity to 'socialize' with other MD children of their own age, and others who mingle with the outside world."

Throughout the sixties, as their elderly parents died, and the disabled children began to take up residence in chronic care facilities, these disabled people began to wonder about the option of Independent Living. The 1966 Souvenir Journal was dedicated to their dream. The cover of the Journal read, "From Bleak Confinement to Cheerful Independence", and depicted the contrast between a hospital ward bed and a totally accessible apartment. The organization, at that time, was raising money to purchase one or two condominium apartments which would be home for a few of the participants of its recreation program. Luckily, ILH was not able to raise enough funds to purchase these apartments.

The Independent Living Services actually began in 1970 when two severely

disabled individuals moved out of a chronic care facility into a public housing apartment in which one of them was living with his mother before her death. After more than six months of negotiating to persuade the facility in which they were living and the NYC Department of Social Services to fund their home attendant, these men were reluctantly 'allowed' to move into this apartment -- only after Independent Living for the Handicapped, Inc. signed a statement which in effect made the organization responsible for the welfare of these two adult men, in case of emergencies, fires, no home attendants, -- for a ninety day experimental period! That was in 1970, and the experiment has proven so successful that the psychologist's report stated that the new living situation had done much to counter the chronic depression usually connected with severe physical disability.

The author relates this incident not only because it is the pilot apartment of this service program, but also to give the reader some perspective on how far society has come in providing services to its physically disabled members. In 1970, two adults were not 'allowed' to leave a chronic care facility to move into their own apartment without a statement by an organization assuming responsibility for their lives. These adults were only allowed to remain in their chosen lifestyle option as a result of a psychologist's evaluation.

The program services grew rapidly after this first apartment was established. Presently, the services of Independent Living for the Handicapped, are available to seventy people in forty apartments scattered throughout New York City. The waiting list is nearly 100 people. The organization has

not been able to meet the needs of the population on the waiting list, primarily due to lack of funds for staff assistance. There are four requirements for eligibility for services: (1) a person in a wheelchair; (2) have relative medical stability; (3) have a desire and need to receive the services; and (4) can qualify for Federal/City/State entitlements to disabled people.

What are the services of Independent Living for the Handicapped which are available to severely disabled people who are living in their own apartments? Primarily, what is available is not a service in se, but a camaraderie, a commitment, an attitude which was apparent in the few sentences written by Mary Weinberger in 1957. This attitude of respect for another person, of responding to another individual as an adult, is paramount to the apparent success of ILH -- and this is attested to by the long waiting list.

However, just as a marriage cannot work solely on love, ILH does not function solely on its attitude. The services of this organization can be grouped into two major categories: (1) those services which it co-ordinates, and advocates for, --services which are available to disabled individuals by right of entitlements; and (2) those services which it provides to assure or facilitate these entitlements. It has been the experience of Independent Living for the Handicapped that these two components are crucial to the independent living of the severely disabled person. This experience has also been documented in the Residential Needs Study, a 1969 Report to the California State Legislature.

INTEGRATED LIVING FOR SEVERELY DISABLED PEOPLE:

What are the services which Independent Living for the Handicapped co-ordinates, and advocates for, on behalf of its consumer population?

(1) Income Maintenance Program: ILH assists the disabled person in securing his SSI entitlements by going with the potential recipient to the Social Security Office to assist in filling out the forms. In addition, ILH calls the SSA Office to move the paperwork along.

(2) Medical Assistance Program: As with SSI, ILH assists the disabled individual in filing for and in getting NYS Medicaid.

(3) Home Health Aide Program: ILH assists the disabled person make application for and secure the funding for an in-home attendant. ILH also negotiates with the NYC Department of Social Services when payments for home attendants are late.

(4) Housing Assistance Program: ILH informs its consumer population of available public housing, as well as such programs as Section 8. In addition, ILH is constantly advocating for more accessible housing at affordable rentals for disabled people. Recently, ILH heard about a new development which announced 100 subsidized apartments for the elderly; when ILH inquired if any of the subsidies were available to disabled people and was informed "No.", a few telephone calls to the HUD area office, the New York City Mayor's Office for the Handicapped, and the newspapers suddenly identified fifteen of those subsidies for disabled people.

(5)Vocational Training Programs: ILH makes referrals to and follow-ups with the NYS Office of Vocational Rehabilitation.

(6) Social and Recreational Programs: ILH informs its consumer population of local voluntary and philanthropic groups which sponsor activities for disabled individuals.

Except for the social and recreation programs provided by local philanthropic groups, the programs listed are basic funding programs for which many disabled people are entitled; however, all of these funding programs -- having money to buy food and clothing, to pay for a prescription, or to pay a home attendant -- are to no avail, if there is no way for the disabled person to take advantage of these entitlements.

Independent Living for the Handicapped assists the severely disabled individual -- the individual who requires moderate-to-maximum assistance to perform his personal life activities, such as: eating, toileting, dressing, and love-making -- attain his entitlements by offering counseling to the disabled person so that he can realize his own abilities, as well as what is available to him. Many of the disabled individuals who first moved into an apartment did so because of the fear of moving into a custodial institution was greater that the fear of living independently. One individual who 'inherited' her apartment when her father walked out on her said, "Of course, I was worried. I really didn't know if I could accept a life on my own. ... But now I love it, and I wouldn't change for anything."

In addition to individual counseling services, both professional and peer counseling, ILH sponsors, twice a month, group tenant meetings in which the tenants discuss problems which they are facing in their apartments. These group meetings are sometimes run by a professional; however, most often are peer run, and the topics discussed range from information giving, such as: how to get food stamps now that the law has been amended, to role playing how to supervise home staff, how to fire someone, how to ask for what is needed

without turning off staff. Individuals give and are given advice on how to deal with the Department of Social Services to find out why a home attendant check is late. It is through these group meetings that the camaraderie which was mentioned previously is developed and nurtured.

In addition to these tenants' meetings, ILH sponsors a weekly Training for Independence group meeting in which individuals who are thinking about getting an apartment, or have recently gotten an apartment, meet to develop their confidences so that they can manage their own apartments. It is in this group, as well as in the casual social get-to-gethers, that individuals select roommates and marriage partners.

Independent Living for the Handicapped has assisted individuals in finding apartments, in determining if the apartments 'really' were architecturally accessible, in evaluating a neighborhood -- its accessibility, through curb cuts, near to an accessible shopping area, near to public transit so that it is easier for employee/attendants to get to their apartments. ILH also assisted in deciding whether or not to ask the management company to make minor architectural modifications to the apartment, before or after the leases were signed. The organization, unlike other independent living programs, does not maintain master leases, and then sub-lets to its consumer group. Leases are signed directly by the prospective tenants; however, in some instances, ILH has been asked to co-sign as a guarantor.

Independent Living for the Handicapped also assists the tenants to find home attendants by maintaining a registry of nursing service agencies

in New York City which will provide home attendants at a cost which its tenants can pay. ILH also sponsors an Emergency Aide Service which can provide an attendant to a person in an apartment, within two hours of the request -- if necessary. Presently, ILH, through its consumer group, is developing a formalized Home Attendant Training Program, which is an outgrowth of the Emergency Aide Service.

Finally, Independent Living for the Handicapped developed a subsidized livery - van - service, at $1.00 a ride so that the disabled individuals of its service could get around the City to shop, socialize, go to movies, museums. This Specialized Livery Service has been very successful in affording the disabled individual the opportunity to feel part of his community. This service is funded through the 'fares' and through the private fund-raising activities of the organization. An average ride which would cost the passenger one dollar cost the organization nearly twenty dollars. The cost is expected to increase greatly this year, as car insurance rates have nearly doubled in the State of New York.

In summary, the services which Independent Living for the Handicapped provides are

(1) a counseling and advocacy service; and advocacy is merely the informing of an individual what are his entitlements, and how to get them, either by assisting him directly to secure his entitlements, or, and preferably, supporting his efforts to secure his entitlements himself. A poster on the author's wall states, "Give me a fish and I eat for a day. Teach me to fish and I eat for a lifetime." Advocacy is like teaching fishing.

(2) an apartment finding service; which includes evaluation of the apartment, as well as the neighborhood, for accessibility;

(3) tenants' meetings, socials, and a Training for Independence group;

(4) assistance in finding, training, and supervising -- if necessary -- home attendants; as well as, an Emergency Aide Service;

(5) a subsidized and specialized livery service. This encourages the individuals to participate in their community activities.

What are the assests of this program model? One, the model of Independent Living for the Handicapped, Inc. offers a program which can grow organically, since it is not restricted by a physical plant size. Secondly, ILH offers a program model in which the consumer of the service has the final word in whether or not to sign a lease on an apartment, whether or not to hire or fire an aide, whether or not to use the Livery Service. Realistically, an individual in an apartment has the final word in whether or not to continue to use the services of the organization. Thirdly, ILH offers a sense of community and participation to the individuals it serves. Fourthly, ILH offers a program model which allows for the maximum integration of disabled and non-disabled individuals, since it expands apartment by apartment -- by two's and three's, not by ten's and twenty's.

What are the deficits of this community-based non-medical model? One, the growth is slow: one apartment at a time. Secondly, there is presently no government funding source for this kind of program, for the constellation factor, for the co-ordination, which is necessary to assist disabled individuals secure their entitlements under the law.

In closing, the author would like to direct the readers attention to the title of the presentation: Integrated Living for Severely Disabled People. The strength and the success of Independent Living for the Handicapped, Inc grows out of the mutual cooperation and relationship -- the integration -- which develops between the disabled and non-disabled members of the organization. The underlying principle and the goal of this organization is beautifully and succinctly stated by individual who moved into the first apartment:

> "If I had to describe to an able-bodied person or any other person for that matter, what it means to be in a wheelchair, ... I think that basically I'd have to say to them that while the wheelchair is obvious and my disability is obvious, that there is a person behind that disability and rather instead of looking at simply a wheelchair--or a person sitting in a wheelchair--to look at me as a person, to accept me as a person."

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